

PUBLIC HEALTH COMMITTEE-HOUSE BILL #6200
AN ACT CONCERNING THE USE OF LONG TERM ANTIBIOTICS FOR THE
TREATMENT OF LYME DISEASE

2/6/09

My name is Stephen Arndt and I live in Woodbridge, CT. I was bitten by an infected tick in June of 2002. Unfortunately, I did not see the tick, but had a large welt followed by a generalized rash-not a bulls eye. In early July 2002, I developed fatigue, fever, persistent and unrelenting headache, and stiff neck. Over the next four weeks, I went to 4 different doctors in CT and one in Maine. Not one diagnosed or even tested for Lyme. After two more weeks, additional problems developed of severe night sweats, shakes, disorientation, brain fog, lock jaw, sore throat and difficulty swallowing. In two instances, I asked the doctors about Lyme disease, each time I was told that I had no large joint stiffness, therefore it was not Lyme. It was now August, 5 weeks have gone by and I am severely ill. In addition, I now had tremors and shakes and my cognitive function was a "dense fog". A family friend and burn nurse from Bridgeport Hospital, came by my house and asked me questions for about an hour. Afterwards, she felt I needed to be tested for Lyme disease. In a week, the results were back from Quest-a highly positive ELISA. This was followed by the Western Blot which showed 80% of bands positive. I was greeted from the doctor with, "so you did have something after all". I was prescribed 3 weeks of doxycycline of 200 mg, twice per day.

I improved rapidly. After 3 weeks, I felt a lot better. Although, upon stopping the antibiotics, my health began to slowly worsen. The doctor who prescribed the antibiotics, said that I had received adequate treatment at this point. I looked in my insurance booklet under Lyme and 1 of 3 approved practices was neurology physicians. There was an office nearby, so I went there. I was told that a spinal tap would determine with 100% accuracy whether I was still infected. The spinal tap was negative and therefore I was told that I no longer have Lyme; "the symptoms are most likely imagined, in my head".

Over the next few months, my health worsened-night sweats, tremors, brain fog and severe headaches, plus tingling in my legs. A co-worker heard about an upcoming lecture on Lyme. It was eye opening and I found a Lyme support group. Finally, some help. They gave me the names of Lyme literate doctors and I attended their meetings. If it were not for this, where would I be today? I got most my life back with the help of these Lyme specialists. I have been seemingly 80%-95% recovered for the last 5 years, and owe so much to them for these years of which my children are now 10 and 14.

In conclusion, it is nightmarish, how hard it was to get adequate treatment. It has been difficult to get medical expenses covered, and you can't get any life insurance or disability once you are labeled "chronic Lyme". I have to travel out of state for adequate care. I have lived this disease for almost 7 years, and there is absolutely no refuting the help of these Lyme literate doctors. It shouldn't need to be such a hidden specialty and so devastating to countless individuals and families-**please** help stop this perpetual problem once and for all. I will help in any way-my medical records- anything.

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